



Paediatric End of Life Care Network (PELiCaN)

**Spiritual Care** 

Spiritual care is an essential part of care. Chaplains are specialists in spiritual care; however, it is the aim of all staff to ensure the spiritual needs of the children, young people and their families are met.

Chaplains are available in hospitals across the NHS & third sector organisations such as CHAS and can provide:

- A safe place to talk
- A listening ear
- Companionship on the journey
- Prayer for you and those you love
- Help contacting faith and community groups
- Help planning funerals
- Bereavement support

Spirituality means different things to different people. Religion and faith might be part of someone's spirituality, but spirituality is not always religious. Everyone has spiritual needs throughout their lives whether they follow a religion or not.

Some people are struggling with big questions and need help to explore and make sense of what is happening in their life. Spiritual care from a paediatric palliative perspective is about journeying with children and families as they explore what is important to them. It is about exploring and holding on to hope and having time to listen without feeling the need to fix.

Looking after a child with a terminal illness can causes people to think about death, loss and grief differently. Some people may want to reflect on the meaning of their life, perhaps more so than at any other time in their life.

Spiritual practice, including religion, may become more important to someone as their child approaches the end of life phase.

Spiritual needs are connected to physical, emotional and social needs too. Studies have suggested that spiritual wellbeing may affect suffering at the end of life. Spiritual assessment and care are therefore very important when caring for a child who is approaching the end of their life.

Spiritual wellbeing is often described as feeling at peace.

Spiritual distress, or spiritual pain or suffering can happen when people are unable to find sources of meaning, hope, love, peace, comfort, strength and connection in their life. This distress can also affect physical and mental health.

Terminal illness can cause spiritual distress in the sick child or young person as well as their family and friends.

Someone might be described as being in spiritual distress or spiritual pain if they are:

- Searching for meaning, for example asking questions such as 'Why is this happening?', 'Why me?', 'Who am I?' and 'How will I be remembered?'
- Becoming more withdrawn and isolated
- Afraid of being alone
- Refusing care
- Saying they feel scared or worried.



# The following is the Hope Assessment Tool for Professionals

Some professionals find it hard to discuss spirituality due to lack of training, not knowing what to say or being concerned about saying something inappropriate. The HOPE assessment tool is a good conversation starter:

#### Hope

• What are your sources of hope, strength, comfort and peace?

### **Organised religion**

- Do you have a religion or faith?
- How important is your faith religion or faith to you?

### Personal spirituality and practices

- What do you do that gives you a sense of meaning and purpose in life?
- In what ways does this add to your sense of identity?

## Effects on medical care and of life issues

- Has being unwell stopped you doing things that give your life meaning and purpose?
- · Are there any specific practices we should know about in providing for your care?

This document has been developed by Rev Amanda Reid, Chaplain, Children's Hospices Across Scotland (CHAS), using adaptations from The Hope Assessment Tool for Professionals, developed at Brown University, Rhode Island, USA. Thank you for your assistance in the development of this guidance.

The PELiCaN Service Development Group have endeavoured to create as complete a document as possible, however, if you have any constructive feedback or comments on this document this would be greatly appreciated. You can do this by emailing the team on <a href="mailto:nss.pelican@nhs.scot">nss.pelican@nhs.scot</a> or by completing the following <a href="mailto:feedback">feedback form</a>. NB- these documents will be subject to NSS document governance and will be subject to regular review.

### NOTE

This guideline is not intended to be construed or to serve as a standard of care. Standards of care are determined on the basis of all clinical data available for an individual case and are subject to change as scientific knowledge and technology advance and patterns of care evolve. Adherence to guideline recommendations will not ensure a successful outcome in every case, nor should they be construed as including all proper methods of care or excluding other acceptable methods of care aimed at the same results. The ultimate judgement must be made by the appropriate healthcare professional(s) responsible for clinical decisions regarding a particular clinical procedure or treatment plan. This judgement should only be arrived at following discussion of the options with the patient, covering the diagnostic and treatment choices available. It is advised, however, that significant departures from the national guideline or any local guidelines derived from it should be fully documented in the patient's case notes at the time the relevant decision is taken.